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Brief Report

The impact of COVID-19 on the lifestyles of adolescents with cerebral palsy in the Southeast United States

Byron Lai, PhD ^{a,*}, Huacong Wen, PhD ^b, Tanvee Sinha, BS ^b, Drew Davis, MD ^a,
Erin Swanson-Kimani, MD ^a, Cynthia Wozow, DO ^a, Raven Young, BS ^a,
Danielle Powell, MD ^b, James H. Rimmer, PhD ^c

^a Department of Pediatrics, Division of Pediatric Rehabilitation Medicine, School of Medicine, University of Alabama at Birmingham, Birmingham, USA

^b Department of Physical Medicine and Rehabilitation, School of Medicine, University of Alabama at Birmingham, Birmingham, USA

^c School of Health Professions, Dean's Office, University of Alabama at Birmingham, Birmingham, USA

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ABSTRACT

Background: The impact of COVID-19 on adolescents with cerebral palsy (CP) and their families is underinvestigated, particularly in the Southeastern United States.

Objective/Hypothesis: The objective of this study was to examine the impact of COVID-19 on lifestyle activities, general and mental health, and basic needs among a cohort of adolescents with CP in the Southeast U.S. The second purpose was to identify key factors that impacted their lifestyles.

Methods: This was a cross-sectional survey of adolescents with CP (aged 10–19 years) who completed a child-modified version of the Coronavirus Disability Survey. Health and behavior items were associated with the perceived lifestyle impact of COVID-19.

Results: A total of 101 respondents completed the survey (mean age: 14 ± 2 years). Respondents reported minimal to no change in general health since the COVID-19 outbreak. Basic needs were met for most families. Nearly all participants (94.1%) reported a mental health concern that resulted from COVID-19: 32.7% felt down or depressed; 47.5% felt little pleasure in doing things; and 64.4% felt isolated. Moreover, 74.3% reported decreased socialization, 51.5% reported reduced exercise participation, and 43.6% reported difficulties in obtaining medical care. Most participants (90.1%) were negatively affected by COVID-19, and key associated factors were reduced interactions with friends and family ($p = 0.001$), exercise participation ($p = 0.016$), interest in doing things ($p = 0.005$), worsened depression ($p = 0.015$), increased isolation from others ($p = 0.02$) and at home ($p = 0.006$), technological communication ($p = 0.00$), and virus exposure ($p = 0.008$).

Conclusions: Study findings highlight problem areas that warrant urgent intervention among adolescents with CP located within the Southeast U.S.

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Few studies have documented the effects of COVID-19 on the lifestyles of people with cerebral palsy (CP) living in the United States (U.S.), particularly among people living in the Southeastern U.S. The Southeast is a geographic region with some of the highest rates of disability and health conditions and people living in rural areas who have low access to health care across the nation (as

reported by the United Health Foundation).¹ Given the region's reportedly low acceptance of COVID-19 vaccinations,² the Southeast is likely at a significant risk of COVID-19–related harm. Anxiety, depression, suicidal ideation, delays in language and motor development, and substantially increased weight gain are examples of COVID-19's negative effects that have been reported from large datasets of the general children population.^{3,4}

At the onset of the coronavirus outbreak, the World Health Organization anticipated that COVID-19 would have a more significant impact on the lives of people with disabilities owing to 1) limited access to health care or information, 2) inability to implement preventative measures, such as hand washing or physical distancing, and 3) an onset or exacerbation of health conditions

Abbreviations: COVID-19, SARS-CoV-2; GMFCS, Gross Motor Functional Classification System; GLTEQ, Godin Leisure-Time Exercise Questionnaire; U.S., United States; CP, Cerebral palsy.

* Corresponding author. Children's of Alabama, ATTN: Byron Lai, 1600 7th Avenue South 5 Dearth, McWane 5601, USA. Fax: 1 +(205) 638-9793.

E-mail address: blai@uabmc.edu (B. Lai).

(e.g., cardiovascular disease, depression, and anxiety) as a result of reduced social interactions and physical activity participation.⁵ These suspicions have since been supported by studies in various disability groups across the globe.^{6–9} One study in Ireland reported that caregivers of children with CP had decreased physical and mental quality of life, and some children discontinued their physical therapy.¹⁰ A French national survey including children with disabilities (42% who had CP) reported that 76% reduced their physical activity participation, 76% were educated at home, and cancellation of medical and therapy appointments was common.⁹ Nevertheless, peer-reviewed publications in the U.S. examining the impact of COVID-19 on the lifestyles of people with disabilities, such as CP, are limited, particularly in the adolescent age range.

Adolescence is a critical period for youth with CP to build their self-identity and adopt vocational skills and health behaviors, which increases the likelihood of them living healthy and independent lifestyles in adulthood.^{11–13} Prior to the SARS-CoV-2 (COVID-19) pandemic, adolescents with CP were found to lag behind in the development of adult life skills (e.g., obtaining housing, employment, developing intimate relationships, and participating in meaningful hobbies)¹⁴ and experienced alarmingly higher rates of isolation and related mental health disorders, such as depression, than peers without CP.¹⁵ They were also reported to engage in far lower rates of health-enhancing social and physical activities.^{11,16–18} These disparities have likely been exacerbated by the shelter-in-place orders and social distancing recommendations developed in response to COVID-19. One study of a cohort of children with motor impairment ($n = 102$) in the Midwest region of the U.S. reported decreased physical activity and functional mobility and increased child and caregiver stress.¹⁹ To the best of our knowledge, no peer-reviewed publication has documented the impact of COVID-19 among children with CP within the Southeast U.S.

The primary purpose of this study was to describe the impact of COVID-19 on perceived health, healthcare and medication access and use, lifestyle activities, exercise behavior, and mental health among a cohort of adolescents with CP from a patient database at a children's hospital in the Southeast U.S. The second purpose was to identify key factors that impacted the lifestyles of adolescents with CP during the pandemic.

Methods

Participants

Prospective participants were prescreened and recruited from medical and billing records of the hospital. Participants were eligible for the study if they were between the ages of 10–19 years and had a medical diagnosis of CP, as determined by International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes. Based on a total of 283 eligible people from billing records of the hospital, we aimed to reach a sample of 99 people to achieve an acceptable margin of error for exploratory and categorical responses at 8% with a confidence level of 95% (study purpose 1).^{20–22} Based on a sample size calculation using G*Power statistical software, a sample size of 99 would also be sufficient for achieving a statistical power of 0.8 for correlational analyses (study purpose 2) assuming the following parameters: Chi-square test, a small to moderate effect size w of 0.29, confidence level of 95%, and 1 degree of freedom. The study was conducted in accordance with the principles of ethical human research as defined in the Declaration of Helsinki and was approved by the University Internal Review Board for Human Use.

Procedures

Consent forms and study surveys were sent via email invitation to the email address on file (typically a caregiver's email) through REDCap (a secure web application for managing online surveys and databases). The email invitation had a clickable link that directed the prospective participant to the study consent form in their web browser. The consent form required digital signatures from a caregiver and the adolescent. The consent form included a notice to waive the need for a separate assent form. After digitally signing the consent form, each participant was directed through the study surveys. After completing the surveys, participants were remunerated with a \$40 gift card that was mailed to their home. Adolescents were instructed to complete the surveys with the supervision of a caregiver. If this was not possible, caregivers were instructed to complete the forms for the adolescent by proxy.

Measures

Participants completed a total of 3 questionnaires that were estimated to last no longer than a total of 45 min. The impact of COVID-19 was measured by a survey that was developed for adults with disabilities, the COVID-19 Disability survey (COV-DIS),²³ which we modified for children (see Appendix A). The original COV-DIS included 34 items that were drawn from other surveys such as the Center for Disease Control and Prevention COVID-19 Community Survey, Osteoporotic Fractures in Men Study, Study of Muscle Mobility and Aging, Understanding America Study, Short-Form Survey 36 items, and the Patient Health Questionnaire-2.

Our team modified the COV-DIS by altering and removing questions to make the survey more suitable for adolescents. First, the lead researcher modified the wording to be more appropriate for an adolescent reading level. Second, the questions were reviewed by a physical medicine and rehabilitation physician. Third, the questions were further modified by an adolescent with CP and mild intellectual disability and his/her caregiver. The modified COV-DIS included 9 questions on participant characteristics or demographics (e.g., age, sex, race/ethnicity, job/student status, household annual income, and residential area) and 18 self-reported items on how COVID-19 has affected them and their lifestyle. Specifically, questions 1 and 2 probed perceived health status and changes in health in response to COVID-19. Mood and mental status were assessed through questions 3–5: little pleasure in doing things, feeling down, and changes in feelings of isolation since the outbreak of COVID-19. Questions 6–10 were related to COVID-19 exposure, testing, knowledge, and how much it affected their lives. Questions 11–18 were related to school, basic needs, medical needs, and changes in daily routine including exercise behavior.

Exercise participation was further measured using the Godin Leisure-Time Exercise Questionnaire (GLTEQ). The GLTEQ²⁴ is a simple 7-day recall, 3-item questionnaire that asked people to self-report the number of bouts of physical activity they performed within the past week that lasted longer than 15 min. There is evidence to support the GLTEQ as a valid and reliable measure of physical activity among adults with multiple sclerosis²⁵ and adolescents.²⁶ Participants also completed a self-report measure of their functional mobility using the Gross Motor Function Classification System (GMFCS) Family Report questionnaire.^{27,28} For the GLTEQ, a health contribution score was calculated per participant, which was used to categorize people as physically active or insufficiently active at baseline. This approach multiplies the strenuous and moderate-intensity exercise values by 9 and 5, respectively.

The products were then summed into a single score. A score of <24 was classified as physically inactive (i.e., not achieving sufficient volumes of physical activity that are likely to elicit meaningful health benefits), whereas a score of ≥24 was considered physically active.²⁹

Analysis

Results from the modified COV-DIS and GMFCS were descriptively reported using means, standard deviations, frequency counts, and percentages where appropriate. To address the second study purpose, Chi-square and Student *t* tests were used to examine associations between the degree of life negatively affected by COVID-19 with participant characteristics and lifestyle factors. The degree of life negatively affected by COVID-19 was evaluated by COV-DIS question 13, which asked how much COVID-19 has negatively impacted the respondent's lifestyle and was scored as follows: 1) "A lot", 2) "A fair amount," 3) "Just a little," 4) "Not at all". All participants were further combined into two groups, 1) "a lot and a fair amount" and 2) "just a little and not at all", owing to the small sample size. Participant characteristics included sex, ethnicity, living area, GMFCS, and annual household income, and lifestyle factors were survey responses related to mental health (less interested in doing things, depression, and isolation), COVID-19, and daily routine activities (responses to questions 19.1–19.7). No multiplicity adjustments were conducted, considering the exploratory nature of the study. Statistical analyses were conducted using IBM SPSS statistical software, version 27.

Results

From 283 families that were contacted, 101 people completed the survey (35.7% respondent rate) between January 1st and June 29th, 2021. Participant characteristics are shown in Table 1. The sample consisted of primarily young adolescents (*M* age = 14 ± 2 yrs), and the sex and ethnicity representations were similar to U.S. Census Bureau demographic estimates in the state of Alabama.³² The sample also consisted of people with a diverse mixture of GMFCS levels and household incomes. GLTEQ scores indicated that the sample included a roughly equivalent mixture of physically active and inactive adolescents, but the sample was generally classified as physically inactive.

General and mental health

Of the 101 participants, 83.2% (n = 84) reported a positive health status, as "excellent" (n = 11), "very good" (n = 36), or "good" (n = 37); 15.2% (n = 15) reported "fair health"; and 2% (n = 2) "poor health". About 85.1% (n = 86) reported that changes in health after COVID-19 was "much better" (n = 6), "somewhat better" (n = 7), or "about the same" (n = 73); 11.9% (n = 6) reported "somewhat worse" health; and 3% (n = 3) reported "much worse." Regarding mental health, 47.5% (n = 48/101) reported little pleasure in doing things (nearly every day = 4; more than half the days = 7; several days = 17; and not at all = 26), 32.7% (n = 33/101) reported feeling down, depressed, or hopeless (nearly every day = 1; more than half the days = 4; several days = 14; and not at all = 35), and 64.4% (n = 65/101) reported feeling more isolated (much more = 21; somewhat more = 16; about the same = 9; somewhat less = 4; and much less = 4) since the onset of COVID-19. Only six people (5.9%) reported that they did not experience any of the three mental health issues (lack of pleasure in doing things, depressed, or hopeless).

Table 1
Participant characteristics (n = 101).

Characteristic	n	%
Sex (male/female/other)	49/51/1	53.7%/52.7%/1%
Age in years (mean [SD])	14 (2.4)	–
Ethnicity		
White	64	63.4%
Black	29	28.7%
Asian	1	1.9%
Other	7	6.9%
Hispanic/Latino	3	3%
Annual household income		
< \$30,000	20	19.8%
\$30,000 – \$59,000	24	23.8%
\$60,000 – \$99,000	21	20.8%
≥\$100,000	16	15.8%
Do not know	5	5%
Prefer not to say	15	14.9%
Gross Motor Function Classification System Level		
I	31	30.7%
II	13	12.9%
III	13	12.9%
IV	29	28.7%
V	15	14.9%
Job status before the pandemic		
Student/unemployed	91	90.1%
Working full-time	7	6.9%
Working part-time	3	3%
Do not know	0	–
Current job status		
Student/unemployed	92	91.1%
Working full-time	6	5.9%
Working part-time	2	2%
Do not know	1	1%
Godin Leisure-Time Exercise Questionnaire		
Health contribution score (mean [SD])	17.9 (19)	–
Physically active (score ≥24)	41	40.6%
Physically inactive (score <24)	60	59.4%

COVID-19–related questions

A total of 35 people (34.7%) reported that they thought they were exposed to COVID-19; 51 (50.5%) reported they had not been exposed; and 14 (13.9%) reported that they did not know. Fourteen respondents (13.9%) reported that they had contracted the virus. Forty-five respondents (44.6%) reported that they were tested for COVID-19. When asked how much their life was affected by COVID-19, 29 respondents (28.7%) reported "a lot," 44 (43.6%) reported "a fair amount," 24 (23.8%) reported "just a little," and 4 (4%) reported "not at all." A total of 25 respondents (24.8%) reported they had trouble getting information they trusted about the virus. Sixty respondents (59.4%) reported having no trouble finding the information they trusted about the virus, and 16 (15.8%) reported they did not know.

Basic needs and lifestyle activities

Results for questions 11–18 are reported in Table 2. Most respondents (74.2%; n = 75) attended school at home through virtual online classes or were home-schooled. Preferences for attending school online or in-person were mixed. Some families (24.8%; n = 25) experienced at least some difficulty in obtaining food. Fourteen respondents (13.9%; n = 14) had at least some difficulty with obtaining medicine. Nearly half of the respondents (43.9%; n = 44) experienced some or a lot of difficulty with obtaining medical care. Most participants (90.1%; n = 91) experienced changes in their daily activities owing to COVID-19, such as home isolation and reduced interaction with friends and family. Daily activities were altered, including groceries, medicine, and food being delivered, as

Table 2
Basic needs and lifestyle activities.

Item	Response	n	%
Question 11 How do you currently attend school	All my classes at school	26	25.7%
	Some of my classes at school and some online	20	19.8%
	All classes online	29	28.7%
	Home school	19	18.8%
	Do not attend	7	6.9%
Question 12 Do you prefer classes online or at school?	Online	29	28.7%
	School	54	53.5%
	Mixture	17	16.8%
Question 13 Difficulty obtaining food	No difficulty	76	75.2%
	Some difficulty	23	22.8%
	A lot of difficulty	2	2%
	Unable or very difficult	0	–
Question 14 Difficulty obtaining medicine	No difficulty	87	86.1%
	Some difficulty	12	11.9%
	A lot of difficulty	2	2%
	Unable or very difficult	0	–
Question 15 Difficulty with medical care	No difficulty	57	56.4%
	Some difficulty	35	34.7%
	A lot of difficulty	9	8.9%
	Unable or very difficult	0	–
Question 16 What changes have you made in your daily routine since the coronavirus outbreak?	Not leaving my house as much	83	82.2%
	Not interacting with friends and family as I used to do	75	74.3%
	Not getting as much exercise	52	51.5%
	Started having food delivered	29	28.7%
	Started having medicines delivered	13	12.9%
	Started connecting with family members and friends more by computer, tablet, or phone	59	58.4%
	Started relying on family and friends to do things for me	18	17.8%
	I have not made any changes	10	9.9%
Question 17 Has the coronavirus pandemic negatively affected the job status of your parent/guardian?	Yes	33	32.7%
	No	68	67.3%
Question 18 Have you or your family ever experienced the following since becoming aware of the coronavirus pandemic?	Not enough money to pay rent/mortgage	10	9.9%
	Not enough money to pay for gas	5	5%
	Not enough money to pay for food	7	6.9%
	Did not have a regular place to sleep or stay	0	–
	We have not experienced any of these?	87	86.1%

well as some reliance on computer, tablet, or mobile phone technology to communicate with friends and family. Additionally, 52 people (51.5%; n = 52) reported reduced exercise participation.

Factors linked with the impact of COVID-19 on respondents' lifestyles

Association results are presented in **Tables 3 and 4**. Compared with participants whose lives were “just a little and not at all” negatively affected by COVID-19, adolescents who reported life was negatively “a lot and a fair amount” impacted by COVID-19 were more likely to be those who had less interest in doing things (25% vs 56.1%, p = 0.005), felt more depressed (14.3% vs 39.7%, p = 0.015), felt more isolation (46.4% vs 71.2%, p = 0.02), felt exposure to the virus (19.2% vs 50%, p = 0.005), left the home less (64.3% vs 89%, p = 0.016), interacted with friends and family less (50% vs 83.6%, p = 0.001), participated in less exercise (32.1% vs 58.9%, p = 0.016), and connected with family/friends more using technology (28.6% vs 69.9%, p = 0). No statistically significant associations were found for participant characteristics.

Discussion

This study examined the impact of the coronavirus pandemic on the lives of adolescents with CP living primarily within the state of Alabama, a state located in the Southeast U.S. with some of the lowest rates of healthcare access and the highest rates of obesity and disability in the U.S. Study findings identified critical areas that have been impacted by COVID-19 that warrant intervention or support from health professionals and local officials. For example, decreased socialization, depression, loss of pleasure in doing things, and hopelessness affected a substantial proportion of adolescents with CP. Some respondents experienced issues obtaining food and medical care.

Descriptive study findings support those presented in prior survey studies. Home isolation, reduced socialization and medical care access, and altered education and mental health have been reported by COVID-19 studies among children with disabilities across the globe.^{9,30,31} For example, a surveillance study in France identified that among a predominant sample of children with CP, 76% were educated at home; 44% stopped or reduced participation

Table 3
Participant characteristics associated with how much life was negatively affected by COVID-19.

Variable	How much life was negatively affected by COVID-19		p-value ^a
	A lot and a fair amount (n = 73)	Just a little and not at all (n = 28)	
Age	13.9 ± 2.4	13.8 ± 2.4	0.77
Gender			0.226
Female	38 (52.8%)	11 (39.3%)	
Male	34 (47.2%)	17 (60.7%)	
Ethnicity			0.562
White	45 (61.6%)	19 (67.9%)	
Non-White	28 (38.4%)	9 (32.1%)	
GMFCS			0.87
Level I	23 (31.5%)	8 (29.6%)	
Level II	9 (12.3%)	4 (14.8%)	
Level III	8 (11%)	4 (14.8%)	
Level VI	23 (31.5%)	6 (22.2%)	
Level V	10 (13.7%)	5 (18.5%)	
Annual household income			0.909
< \$30,000	15 (20.5%)	5 (17.9%)	
\$30,000	15 (20.5%)	5 (17.9%)	
\$59,000	18 (24.7%)	6 (21.4%)	
\$60,000	15 (20.5%)	6 (21.4%)	
\$99,000	10 (13.7%)	6 (21.4%)	
GLTEQ HC score	19.3 ± 20.2	14.4 ± 16	0.253
Living area			0.835
Big city or suburb	21 (29.6%)	7 (25.9%)	
Small city or town	32 (45%)	14 (51.9%)	
Rural	18 (25.4%)	6 (22.2%)	

NOTE. GMFCS: Gross Motor Function Classification System; GLTEQ HC: Godin Leisure-Time Exercise Questionnaire Health Contribution. Values are mean ± SD or n (%).

^a Indicates significance at alpha level 0.05. Comparison across groups using chi-square or Student t tests, as appropriate.

in physical activities, and 44% reported reductions in morale. Moreover, a survey of 241 children with disabilities in the UK reported a variety of negative changes in mood and behavior after the pandemic.³³ One study that surveyed children with physical and intellectual disability in New York⁸ demonstrated similar reductions in physical activity participation (61% of the sample) and

negative impacts on mental health (65%). A recent study for caregivers of children with CP demonstrated that general mental and physical health and communication declined among approximately 50% of the sample.¹⁰ In the Midwest U.S., a study including 102 children with motor impairment reported a 36% reduction in receiving therapies, as well as a substantial proportion of children

Table 4
Lifestyle factors associated with how much life was negatively affected by COVID-19.

Variable	How much life was negatively affected by COVID-19		p-value ^a
	A lot and a fair amount (n = 73)	Just a little and not at all (n = 28)	
Q3. Felt less interest in doing things			0.005 ^a
Yes	41 (56.1%)	7 (25%)	
No	32 (43.9%)	21 (75%)	
Q4. Felt more depressed			0.015 ^a
Yes	29 (39.7%)	4 (14.3%)	
No	44 (60%)	24 (85.7%)	
Q5. Felt more isolated			0.02 ^a
Yes	52 (71.2%)	13 (46.4%)	
No	21 (28.8%)	15 (53.6%)	
Q6. Felt they were exposed to the virus			0.008 ^a
Yes	30 (50%)	5 (19.2%)	
No	30 (50%)	21 (80.8%)	
Q14. Attended school onsite or home			0.824
Onsite	20 (28.2%)	7 (25.9%)	
Home	51 (71.8%)	20 (74.1%)	
Q19.A. Left the home less			0.016 ^a
Yes	65 (89%)	18 (64.3%)	
No	8 (11%)	10 (35.7%)	
Q19.B. Interacted with friends and family less			0.001 ^a
Yes	61 (83.6%)	14 (50%)	
No	12 (16.4%)	14 (50%)	
Q19.C. Participated in less exercise			0.016 ^a
Yes	43 (58.9%)	9 (32.1%)	
No	30 (41.1%)	19 (67.9%)	
Q19.F. Connected with family/friends more using technology			0 ^a
Yes	51 (69.9%)	8 (28.6%)	
No	22 (30.1%)	20 (71.2%)	

NOTE. Comparison across groups using chi-square test.

^a Indicates significance at alpha level 0.05.

who reported increased mental stress.¹⁹ The present study added to this knowledge by providing a more in-depth evaluation of COVID-19-affected lifestyle behaviors. Further research is necessary to explain reductions in mental health and physical activity behavior and, most importantly, how to improve these issues among adolescents with CP in the post-COVID-19 era.

On a positive note, respondents' lifestyles appeared most affected by changes in their behaviors, as opposed to illness. Only 14 respondents (13.9%) reported having contracted COVID-19, and 35 respondents reported being exposed (34.7%). Contracting COVID-19 is generally concerning among people with CP because respiratory illness is a leading cause of morbidity and mortality in this population.³² Instead of declines in physical health, study findings suggested that mental health and healthy behaviors, including in-person socialization, community activity (e.g., going to grocery stores instead of ordering food), and exercise were key lifestyle factors that were altered by COVID-19.

Nearly half of the sample reported decreased exercise participation, which was similar to that reported among children with CP in the Midwest U.S.¹⁹ This is an alarming finding because adolescents with CP have been found to participate in far lower levels of health-enhancing exercise compared with adolescents without CP prior to the pandemic.^{11,16} As a result of rapid deconditioning, exercise levels have likely reached new lows with concomitant declines in health and physical function as a result of rapid deconditioning.³³ Further research is needed to understand the factors that contribute to exercise decline among adolescents with CP in the post-COVID-19 era, as well as strategies that can successfully improve exercise participation.

The second study purpose aimed to identify key factors that were associated with a person's lifestyle being negatively impacted by COVID-19. Study findings demonstrated that less interactions with friends and family and increased communication through technology resulted in greater perceived negative impact of COVID-19. These factors were likely the result of home quarantine, school and facility closures or occupancy limits, and recommendations to social distance that were widespread in Alabama at the time of the study. Although we are unable to explore the cause of increased telecommunications leading to negative lifestyles, a likely explanation was stress and burnout associated with overwhelming volumes of telecommunication and online learning.³⁴ Other key factors were loss of interest in doing things, depression, isolation, reduced exercise participation, and exposure to the virus. We were unable to locate any other academic articles that presented similar findings for children with CP. Collectively, these findings imply that socialization with friends and family, mental or emotional health, and exercise participation are key factors that should be prioritized in interventions, which aim to reduce the perceived impact of COVID-19 among the lifestyles of adolescents with CP. One intervention recommendation could be to improve these factors through telehealth (e.g., remote exercise promotion or therapy and psychological counselling). Advantages of a telehealth approach over usual care include increased social support and access to services,^{35,36} benefits that are particularly useful in the Southeast, where transportation and geographic location are substantial barriers to accessing health care. It is important to note that study findings only *identified* key factors. Study findings did not provide an in-depth explanation into how these factors could be optimally addressed or how the factors were related to each other. These questions were beyond the purview of the study and require further research.

Limitations

This study findings included people who were recruited from a children's hospital within the southeast U.S. (a location with low

access to medical care and high rates of disability and primary health conditions), thereby rendering the study findings generalizable only within this context. Moreover, while we instructed both adolescents and a caregiver to complete the electronic survey together, we did not record or confirm that this occurred, which could have affected the resultant responses. Additionally, we did not conduct statistical corrections for multiple imputations (e.g., Bonferroni correction) and, thus, the results should be interpreted with caution.

There were also a few limitations with the surveys used. The COV-DIS survey was developed to learn about the experiences of people with disabilities during the COVID-19 pandemic. Its objectives were to provide data on general and psychological well-being and daily activities, all of which have likely been exacerbated by the COVID-19 pandemic. Using this survey or a modified version of it is a limitation because it is not yet validated, and the psychometric properties have not yet been established. However, many of the questions in the survey were selected from well-established and validated surveys. Additionally, we chose to include the GLTEQ as a measure of physical activity owing to it requiring only 5–10 min to complete, but it and the health contribution score cut point we chose were not validated in adolescents with CP. There are very few surveys with strong psychometric properties to capture physical activity among adolescents with CP.^{37,38} The survey instrument with the strongest psychometric properties in measuring physical activity among children with CP is likely the Children's Assessment of Participation and Enjoyment (CAPE). Reviews have reported that the CAPE has adequate evidence of validity (construct and content) and reliability (internal consistency, intrarater reliability, and test-retest reliability) to support its use among adolescents with CP.^{37,39} However, the CAPE requires 40 min to complete, which was not practical for the present study.

Lastly, in terms of timing, this study was conducted throughout the COVID-19 pandemic and relies on participant recall in comparing their life at the time of filling out the survey to before the COVID-19 pandemic. A clearer within-subject comparison would have been to compare the survey responses during the pandemic to those measured prior to the pandemic, but this would have been impossible.

Conclusion

The present study provides a snapshot at one time point of the impact of COVID-19 on adolescents with CP, an underrepresented group within the published literature. The surveys were completed primarily during the height of the coronavirus pandemic when vaccines were starting to be delivered to older adults. For most of the study respondents, vaccines were largely not available to middle-aged adults or children. Study findings highlight mental concerns and lifestyle factors that warrant further research and urgent intervention efforts.

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Conflicts of interests

The authors report no conflicts of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2021.101263>.

References

1. United Health Foundation. America's health rankings annual report, 2017 Edition. https://assets.americashealthrankings.org/app/uploads/ahrannual17_complete-121817.pdf; 2017.
2. Nguyen KH, Nguyen K, Corlin L, Allen JD, Chung M. Changes in COVID-19 vaccination receipt and intention to vaccinate by socioeconomic characteristics and geographic area, United States, January 6 – March 29, 2021. *Ann Med*. 2021;53(1):1419–1428.
3. Viola TW, Nunes ML. Social and environmental effects of the COVID-19 pandemic on children. *J Pediatr*. 2021. S0021-7557(21)00122-00124.
4. Lange SJ, Kompaniyets L, Freedman DS, et al. Longitudinal trends in body mass index before and during the COVID-19 pandemic among persons aged 2–19 Years – United States, 2018–2020. *MMWR Morb Mortal Wkly Rep*. 2021;70(37):1278–1283. <https://doi.org/10.15585/mmwr.mm7037a3>.
5. World Health Organization. Disability considerations during the COVID-19 outbreak. Available at: <https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1>. Accessed March 9, 2020.
6. Gleason J, Ross W, Fossi A, Blonskyu H, Tobias J, Stephens M. The devastating impact of COVID-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst, Innovations in Care Delivery*. 2021;2(4).
7. Lebrasseur A, Fortin-Bédard N, Lettre J, et al. Impact of COVID-19 on people with physical disabilities: a rapid review. *Disabil Health J*. 2021;14(1):101014, 2021/01/01/.
8. Theis N, Campbell N, De Leeuw J, Owen M, Schenke KC. The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. *Disabil Health J*. 2021;14(3):101064.
9. Cacioppo M, Bouvier S, Bailly R, et al. Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: the ECHO French survey. *Ann Phys Rehabil Med*. 2020;101429.
10. Cankurtaran D, Tezel N, Yildiz SY, Celik G, Unlu Akyuz E. Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine. *Ir J Med Sci*. 2021:1–8.
11. Waltersson L, Rodby-Bousquet E. Physical activity in adolescents and young adults with cerebral palsy. *BioMed Res Int*. 2017, 8080473.
12. Chamberlain MA, Kent RM. The needs of young people with disabilities in transition from paediatric to adult services. *Eura Medicophys*. Jun 2005;41(2):111–123.
13. Hallum A. Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Curr Probl Pediatr*. 1995;25(1):12–50.
14. Donkervoort M, Wiegerink DJHG, Van Meeteren J, Stam HJ, Roebroek ME, Transition Research Group South West N. Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol*. 2009;51(1):53–62.
15. Downs J, Blackmore AM, Epstein A, et al. The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol*. 2018;60(1):30–38.
16. Shkedy Rabani A, Harries N, Namoori I, Al-Jarrah MD, Karniel A, Bar-Haim S. Duration and patterns of habitual physical activity in adolescents and young adults with cerebral palsy. *Dev Med Child Neurol*. 2014;56(7):673–680.
17. Carlon SL, Taylor NF, Dodd KJ, Shields N. Differences in habitual physical activity levels of young people with cerebral palsy and their typically developing peers: a systematic review. *Review. Disabil Rehabil*. 2013;35(8):647–655.
18. Blackman JA, Conaway MR. Adolescents with cerebral palsy: transitioning to adult health care services. *Clin Pediatr*. 2013;53(4):356–363.
19. Sutter EN, Francis LS, Francis SM, et al. Disrupted access to therapies and impact on well-being during the COVID-19 pandemic for children with motor impairment and their caregivers. *Am J Phys Med Rehab*. 2021;100(9):821–830.
20. Brewer K, Gregoire TG. Introduction to survey sampling. In: *Handbook of Statistics*. Elsevier; 2009:9–37.
21. Ahmad H, Halim H. Determining sample size for research activities. *Selangor Bus Rev*. 2017;2(1):20–34.
22. Dillman DA, Smyth JD, Christian LM. *Internet, Phone, Mail, and Mixed-Mode Surveys: The Tailored Design Method*. John Wiley & Sons; 2014.
23. Bernard A, Weiss S, Stein JD, et al. Assessing the impact of COVID-19 on persons with disabilities: development of a novel survey. *Int J Publ Health*. 2020;65(6):755–757.
24. Shephard R. Godin leisure-time exercise questionnaire. *Med Sci Sports Exerc*. 1997;29(6):S36–S38.
25. Sikes EM, Richardson EV, Cederberg KJ, Sasaki JE, Sandroff BM, Motl RW. Use of the Godin leisure-time exercise questionnaire in multiple sclerosis research: a comprehensive narrative review. *Disabil Rehabil*. Jun 2019;41(11):1243–1267.
26. Zelener J, Schneider M. Adolescents and self-reported physical activity: an evaluation of the modified Godin Leisure-Time Exercise Questionnaire. *Int J Exerc Sci*. 2016;9(5):587–598.
27. Rackauskaite G, Thorsen P, Uldall PV, Ostergaard JR. Reliability of GMFCS family report questionnaire. *Disabil Rehabil*. 2012;34(9):721–724.
28. Ramrit S, Yonglithipagon P, Janyacharoen T, Emasithi A, Siritariwat W. The Gross motor function classification System family report questionnaire: reliability between special-education teachers and caregivers. *Dev Med Child Neurol*. 2017;59(5):520–525.
29. Amireault S, Godin G. The Godin-Shephard leisure-time physical activity questionnaire: validity evidence supporting its use for classifying healthy adults into active and insufficiently active categories. *Percept Mot Skills*. 2015;120(2):604–622.
30. Dickinson H, Yates S. *More than Isolated: The Experience of Children and Young People with Disability and Their Families during the COVID-19 Pandemic*. Melbourne, Australia: Children and Young People with Disability Australia (CYDA); 2020.
31. Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? *J Autism Dev Disord*. 2020;51:1772–1780.
32. Brandenburg JE, Fogarty MJ, Sieck GC. Why individuals with cerebral palsy are at higher risk for respiratory complications from COVID-19. *J Pediatr Rehabil Med*. 2020;13:317–327.
33. Rimmer JH, Schiller W, Chen MD. Effects of disability-associated low energy expenditure deconditioning syndrome. *Exerc Sport Sci Rev*. 2012;40(1):22–29.
34. Mheidly N, Fares MY, Fares J. Coping with stress and burnout associated with telecommunication and online learning. *Front Public Health*. 2020;8:672.
35. Jennett PA, Affleck Hall L, Hailey D, et al. The socio-economic impact of telehealth: a systematic review. *J Telemed Telecare*. 2003;9(6):311–320.
36. Ben-Pazi H, Beni-Adani L, Lamdan R. Accelerating telemedicine for cerebral palsy during the COVID-19 pandemic and beyond. *Front Neurol*. 2020;11, 746-746.
37. Capiro CM, Sit CH, Abernethy B, Rotor ER. Physical activity measurement instruments for children with cerebral palsy: a systematic review. *Dev Med Child Neurol*. 2010;52(10):908–916.
38. Johansen M, Rasmussen HM, Lauruschkus K, Laugesen B. Measurement of physical activity in children and adolescents with cerebral palsy: a scoping review protocol. *JBI Evid Synth*. 2021;19(9):2339–2349.
39. Clanchy KM, Tweedy SM, Boyd R. Measurement of habitual physical activity performance in adolescents with cerebral palsy: a systematic review. *Dev Med Child Neurol*. 2011;53(6):499–505.